

Evaluating a vertical nurse-led service in the integration of palliative care in a tertiary academic hospital

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Abstract

Background: Groote Schuur Hospital is a large Academic Hospital in South Africa that is in the process of integrating palliative care (PC) via a vertical nurse-led doctor-supported (VNLDS) service that was initially established to deliver clinical care. PC integration should occur across multiple dimensions and may result in variable degrees of integration between levels of the healthcare system. This research evaluates the VNLDS through a theory-driven evaluation to describe how the service affected integration.

Methods: A mixed-method sequential design consisting of a narrative literature review on the theory of integration and PC, retrospective quantitative data from a PC service delivery database, qualitative data from semi-structured interviews and document analyses. It was structured in three phases which assisted in confirming and expanding the data. Statistical analyses, deductive thematic coding and documentary analyses were conducted according to the conceptual framework of PC integration.

Results: The PC integration process was facilitated in the following ways: (i) the service provided good clinical PC; (ii) it was able to integrate on a professional level into specific diseases, such as cancer but not in all diseases; (iii) developing organizational structures within the service and (iv) the observed benefit of good clinical care increased the value stakeholders assigned to PC, thereby driving the adoption of PC. However, there are still clinicians who do not refer to PC services. This gap in referral may be grounded in assumptions and misconceptions about PC, especially at the organizational level.

Discussion: Observed PC service delivery is core to integrating PC across the healthcare system because it challenges normative barriers. However, the VNLDS could not achieve integration in leadership and governance, education and hospital-wide guidelines and policies. Whole system integration, foregrounding organizational commitment to PC excellence, is core to integrating PC.

Conclusion: The VNLDS service has effectively linked PC in specific disease profiles and normalized the PC approach where healthcare workers observed the service. These integrational gaps may be grounded in assumptions and misconceptions about PC, especially at the organizational level.

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Plain language summary

How does a nurse led palliative care service affect palliative care integration in a big teaching hospital?

This article evaluates a nurse led doctor supported service in providing palliative care and how it affected the integration of palliative care in an Academic Hospital in South Africa. This study will help us understand the goals of integration, the extent of integration achieved by this service and how and why it was achieved or not.

Keywords: Academic Teaching Hospital, functional, integration, normative, nurse-led

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Introduction

Access to palliative care (PC) services is recognized as fundamental in the continuum of care; unfortunately, there is limited access to these services, especially in low-middle-income countries (LMIC).¹⁻³ Multiple integration strategies are being used to integrate PC services and it is essential to evaluate how strategies work, especially in LMIC where the needs are so great.⁴ Groote Schuur Hospital (GSH) is a large Academic Teaching Hospital (ATH) in South Africa that is in the process of integrating PC.⁵ For the past 10 years, a PC service has been provided by a vertical nurse-led doctor-supported (VNLDS) service in the hospital. The provision of PC services in an ATH is aligned with the South African National Policy Framework and Strategy for Palliative Care Policy (NPFSPC) based on the World Health Assembly 67.19 PC resolution, which provides guidelines on PC service delivery in hospitals.^{1,6} Furthermore, this Framework describes PC in an ATH as *'a specialist palliative care service at regional and tertiary hospitals. Centres of excellence will be established at academic hospitals to support education and research in palliative care'*.⁶ Therefore, the role of a PC service in an ATH extends beyond the provision of clinical care. The NPFSPC was adopted in 2017, and the PC service in GSH had, thus, been started without policy guidance and may provide a service different from that envisaged in the policy. Therefore, it is essential to evaluate this service to identify gaps in its integration process and establish how and why it was or was not achieved.

Gröne and Garcia-Barbero⁷ state that integration is *'the act of making a whole out of parts; the coordination of different activities to ensure harmonious functioning'*. Integration is the process, methods and tools to achieve the harmonious functioning of the different dimensions of a healthcare system.^{8,9} These different dimensions need to be coordinated to ensure patients and families have access to PC when they need it. These dimensions are complex and interlinked and there are a number of theories describing them. This research draws from Valentijn's so-called *'Rainbow Model of Integrated Care'*. Valentijn *et al.*¹⁰ linked integrated clinical health care with an integrated health system. This framework

takes account of the dynamic nature of a health system and the non-linear patterns of integration.¹⁰ It identifies six integration dimensions, namely, clinical, professional, organizational, system integration, functional and normative integration. According to this model, integration of services can happen at different levels, namely micro (clinical integration), meso (professional and organizational integration) and macro (system integration). In addition, Valentijn's theoretical framework also discusses that integrative care requires normative integration at all levels of care. It is the final step to integration and describes the development of mutual values, vision, trust and culture. Valentijn *et al.*¹¹ also describe functional integration as including key support functions and activities structured around the service to ensure accountability and decision-making. Functional and normative integration are interconnected at all levels,¹¹ and the prevailing hospital organizational culture plays a vital role across all these levels.

Organizational culture is a complex phenomenon, universal but challenging to define, dynamic and indistinct.¹² Martin describes it as shared sets of understanding and meaning guiding behaviour and social interactions in a particular organization.¹³ *'This is the way things are done around here'* is a layman's and easily understandable description of organizational culture.¹² Therefore, formal change may be easily introduced, for example, a new policy or dress code, but the unwritten values and rituals must be tackled with sensitivity and understanding. For this reason, disruption of *'how we always do things'* in an organization is not always welcomed and can be met with the marginalization of a new intervention.¹⁴ For example, PC challenges stakeholders to acknowledge the suffering and death of patients, and, sometimes, their mortality. This produces uncomfortable feelings and may even disrupt an individual's way of thinking about their discipline. Thus, the integration of PC into the culture of an ATH and the normalization of PC may be one of the most significant dimensions of integration. There is a need to evaluate both functional and normative integration, and especially culture when evaluating a new service, such as the VNLDS.

The integration process may also vary in the ‘intensity’ thereof may vary depending on the unit of care.¹⁵ Some stakeholders may prefer activities to be linked with an adequate referral process only with good communication between the referring service and the PC service.¹⁵ Other stakeholders would prefer activities to be coordinated where clinical information is shared to manage the transition of patients between different units, such as a multidisciplinary meeting. Furthermore, stakeholders will not engage in PC interventions deemed inappropriate and unresponsive to their and their patients’ needs.¹⁶ In addition, these clinical needs cannot be addressed in isolation – for example, patients cannot be referred to a unit unless the unit forms part of the hospital’s standardized referral process, which requires technology, standard operating procedures and monitoring.¹⁷ This is especially true in an ATH, where functions are too complex to operate only in one domain. Therefore, achieving in-depth, appropriate, responsive but sustainable PC health service integration may require further health system integration. Kaasa *et al.*¹⁸ recommend that PC integration in oncology needs to have both vertical and horizontal aspects as well as multi-dimensional integration.

To manage the complexities of providing PC, a dedicated PC team works in GSH. It currently consists of two PC-trained professional nurses (one acting as a coordinator), two auxiliary social workers, an administrator and two volunteer PC-trained medical doctors. This research evaluated the ability of VNLDS services to strengthen the integration of PC in ATHs in South Africa. Understanding why and how things happened during the development and implementation of the VNLDS is essential to the evaluation. Principles of a theory-driven evaluation are used to gain information additional to the performance and merit of the program.¹⁹ This approach was chosen because an experimental evaluation may not reveal how and why the strategies brought about the change. Astbury and Leeuw²⁰ state that how programmes bring about change is called ‘unpacking the black box’ to explore the inner components and logic of programmes.^{20,21} Although counterfactual evidence is important in an evaluation, the national policy implies that there should be no ATH without a PC-integrated service.⁶ Furthermore, PC is a complex intervention and its integration into the ATH may be influenced by multifaceted aspects, for example, individual, hospital and societal factors.²² Most

importantly, understanding causal pathways of integration may assist with identifying improvements needed as well as implementing the strategies in other settings.

A conceptual framework was developed by drawing on Valentijn’s theory on integration and its dimensions, further literature on integration as well as PC integration.¹⁰ This was developed in the research team and speaking with PC advisors in the field. We can thus conceptualize that a VNLDS service affected functional integration in the functional domains and dimensions, as illustrated in Table 1.

Contextual factors include the environment it is being integrated into, such as the PC need, patient issues, existing frontline services, resources as well as governance structures. In this research, these multiple factors can be further organized into clinical care as well as professional, organizational and systems integration to distinguish the aspect of integration. Having introduced these different factors, normalizing PC by addressing the organizational culture remains core.^{11,12}

In this evaluation, organizational culture refers to the norms, values and behaviour that stakeholders have towards working with patients with life-threatening illnesses, the assumptions they have regarding PC and its role in the health system. Their vision and goals of PC integration form part of the normative process of integration.¹⁰

The research aims to evaluate how a vertical nurse-led doctor-supported PC team served as a strategy to integrate PC into GSH. To make recommendations regarding an effective strategy for integration, it is important to evaluate current PC integration implementation strategies and how they align or do not align with contextual factors, as well as functional and normative integration.

Methodology

A mixed-method sequential design was followed, synthesizing retrospective quantitative data from a PC service delivery database (PC REDCap), qualitative data from semi-structured interviews and document analyses. This research was conducted from March 2020 to July 2022. A narrative literature review was conducted prior to the study to understand PC integration in hospitals and how it can be achieved. The conceptual framework for the research study draws from the

Table 1. Domains of PC integration drawing from multiple sources.

Domains	Dimension of palliative care integration
The provision of patient and family-centred care ^{10,23}	<ul style="list-style-type: none"> • Pain and symptom management • Psycho-social and spiritual care • Informed and participatory decision-making • Family are active members of the team • Bereavement care available • Patient and family education
The provision of collaborative care ^{10,23}	<ul style="list-style-type: none"> • Automatic triggers to initiate palliative care • Multidisciplinary care • Continuity of care • End-of-life care
Information systems ¹⁶	<ul style="list-style-type: none"> • Monitoring and evaluation tools • Integrated reporting mechanisms
Education ^{10,24,25}	<ul style="list-style-type: none"> • Basic • Intermediate • Advanced • Multidisciplinary • Continuous medical education
Leadership and governance ^{10,24,25}	<ul style="list-style-type: none"> • Strategic plan for PC • Managerial oversight and accountability • Financial and resource support • Clinical leadership
Guidelines and policies ^{25,26}	<ul style="list-style-type: none"> • Integrated policies • Stand-alone PC policies
Palliative care workforce ²⁵	<ul style="list-style-type: none"> • The availability of a multidisciplinary PC-trained workforce. • Emotional and organizational support for the palliative care workforce
Drug availability ^{25,27}	<ul style="list-style-type: none"> • Essential medication as specified by the WHO Essential PC Medicine list
Research ²⁵	<ul style="list-style-type: none"> • PC-specific research • Integrated PC research
PC, palliative care.	

Rainbow Model of Integrated Care and the principles of PC.^{10,18,25} This research was conducted in GSH, a large tertiary/quaternary academic hospital with 975 beds, which serves the Cape Metropole and attracts patients from across South Africa for specialized care. It is also a training hospital supporting both undergraduate and postgraduate education and a centre for research.

In phase I, demographic and clinical quantitative data were extracted from a REDCap database from the period January 2017 to June 2021. It was analysed statistically to describe the profile of the referred patients, the sources and timeline of the referrals, the PC services rendered to the patients and families, as well as the discharge

process. The provincial data centre was also approached to access the date of death.

Also, in phase I, semi-structured interviews ($n = 5$) were conducted with VNLDS staff to describe the services delivered in 2022. Face validity of the interview guides was ensured by presenting the questionnaire to experts in the field of normative and functional integration and experts in the field of PC. Construct validity was derived by aligning this tool with the theoretical framework. The methodological triangulation of data strengthened trustworthiness by asking permission from sources about using information obtained outside the formal research process and sharing results with participants before any publications.²⁸ This

is embedded research; therefore, assumptions held by the researcher were explored before commencing data collection *via* a recorded reflective interview between the researcher and supervisors. Reflexivity was further ensured by the researcher and research assistant keeping journals with short notes on discussions, as well as after interviews.

The qualitative data from the staff interviews were analysed using the framework analysis approach using deductive coding.²⁹ The interviews were transcribed and imported into NVivo version 14.23 (Lumivero). The researcher familiarized herself with and immersed herself in data sources. The coding framework was developed from the conceptual framework as discussed in the 'Introduction', drawing from Valentijn's theory on integration.¹⁰ Themes and sub-themes identified in the analysis of the interviews were coded. Codes and analyses were discussed with the supervisors and research assistant and attention was given to emerging themes not identified by the framework so as not to overlook any data. Negative cases or outliers were included and discussed. Codes were also discussed with advisors to check for bias of the researcher. These codes were applied to all the data sources and the data were charted across all the data sources of the study. Selected representative data were used to illustrate the resulting themes of the analysis.^{30,31}

In phase II, analysis from the database and the interviews with the VNLDS service were merged, and these findings were discussed with the VNLDS staff to confirm and explain the data. This assisted in connecting with organizational documentation ($n=14$) (see Appendix A) that explains and confirms the service delivery. The documents were thematically analysed using deductive coding and drawing from the conceptual framework as discussed in the 'Introduction'. A data extraction sheet was used to analyse documents with regard to the name of the document, how, when and why the document is used, and for themes of functional and normative integration. Where PC is/is not in the document and how it is referred to. These factors were further supported by discussing them with the research team.

The data were further expanded by identifying wards and services with distinct referral patterns. The wards with limited PC were determined by listing all wards in GSH and discussing with the PC staff the logical explanation for limited

referral to PC in these wards. For example, it is understandable that there will be limited PC referrals from an ophthalmology ward. If there was incongruence between the disease profile of patients in the wards and the number of referrals, interviews were conducted with staff from those units. These sequential interviews ($n=5$) were conducted with purposively selected senior ward staff outside the PC service. Interviews were performed using a semi-structured interview guide drawing from the conceptual framework, analyses of the VNLDS interviews, database and PC literature.

Finally, all the data sets were integrated to evaluate the effect of the VNLDS in both the different domains. These findings were discussed with an independent observer and with the VNLDS.

Figure 1 illustrates how, in Phase I, quantitative and qualitative were merged to expand on the phenomena. Further interviews and document analyses were done to explore the findings further. If all four data sets confirmed the findings, it was deemed to be strong convergent evidence and if one dataset did not confirm the findings, it was reported as divergent evidence. The merging of the data and the inferences drawn from the data was done in discussion with the research team. The details of the merging and inferences are attached in Appendix A.

Results

Results from the integrated findings are presented in nine main clusters concurrently, as described by the conceptual framework and the dimensions of integration.

Clinical profile of referred patients and dimensions associated with clinical integration

This dimension explores person-focused care provided by the PC service.

The provision of patient and family-centred care

The literature review found that clinical PC is provided when patients and families receive pain and symptom control; psycho-social and spiritual care, informed participatory decision-making; and families are informed and are seen as part of the care team; patient and family education is provided; and bereavement care is provided.^{18,25,27}

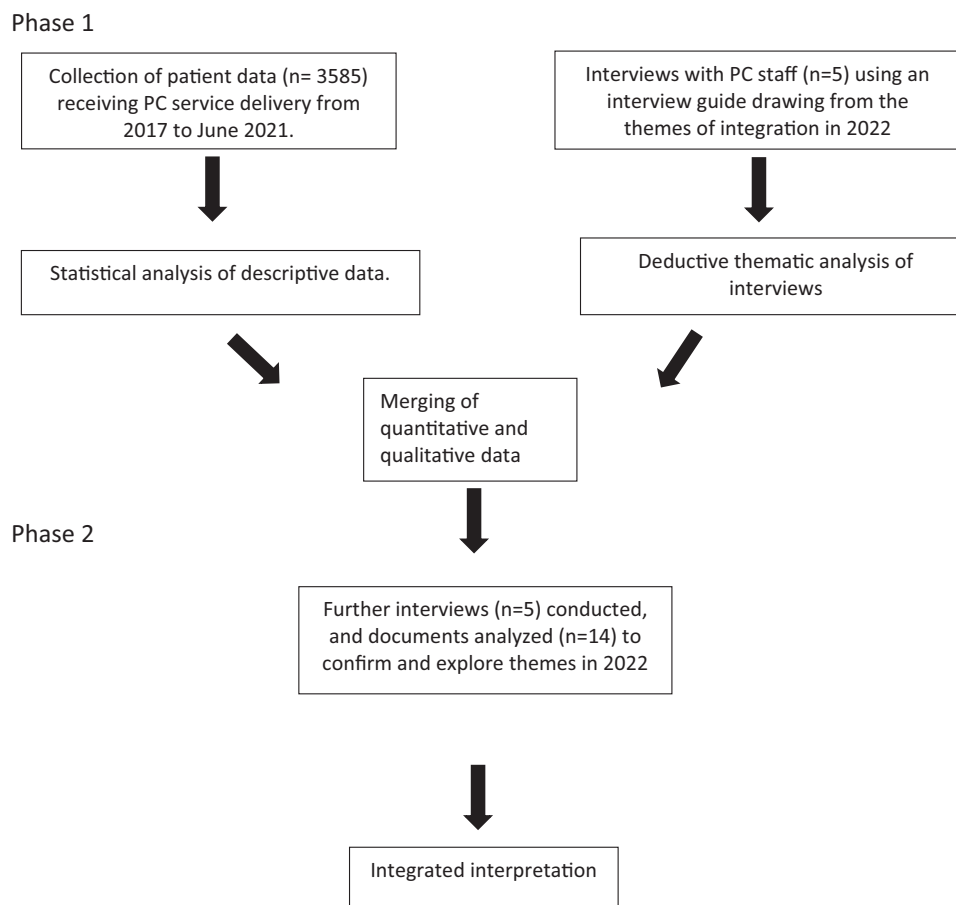


Figure 1. Schematic representation of the methodology.

Clinical PC service delivery. Interviews with the VNLDS staff indicated that the VNLDS delivers a consultancy service across the whole hospital. There is evidence of increasing numbers of patients being referred to the VNLDS service from across the hospital with multiple conditions. The majority of patients were bedbound (43%) or required assistance (41%), with very few being fully mobile (15%). On average, 58% of PC patients were referred specifically for end-of-life care as a reason for referral. However, this decreased from 91% in 2017 to 36% in 2021 (see Table 2). Other reasons for referral are comprehensive care, including symptom control, counselling, education, social support and placement.

Reviewing available mortality data ($n=1894$) of these referred patients on the REDCap database, most patients (53%) were referred in the last week of life. See Figure 2.

The data centre confirmed that place of death of ($n=1188$), 27% of patients died in hospitals

(Table 3). It further confirmed that 191 (16%) died at home. The data centre could only provide the death data for 33.1% of patients because home deaths are not always recorded on the provincial data system, which is not linked to the Department of Home Affairs, where deaths are recorded. All hospital death data are available; if no place of death is recorded, we can assume the place of death is home.

Pain and symptom control

There is strong converging evidence from the database, document review and interviews that patients referred to the VNLDS receive pain and symptom control. The database indicated that 97% of the referred patients received pain and symptom control.

This is further supported by evidence of routine pain and symptom control in document review of the PC stationery. There is also evidence that

Table 2. Referral data to the PC service from 2017 to June 2021 (REDCap database).

	2017 (n=737)		2018 (n=593)		2019 (n=773)		2020 (n=931)		2021 (until June) (n=551)		Overall (n=3585)	
	n	%	n	%	n	%	n	%	n	%	n	%
Referring ward												
Surgical wards	104	14.1	120	20	190	24.6	249	26.7	159	29	822	22.9
Medical wards	283	38.4	240	40	335	43.3	313	33.6	184	33	1355	37.8
Gynaecology	11	1.5	19	3	29	3.8	48	5.2	21	4	128	3.6
Emergency unit	175	23.7	100	17	81	10.5	63	6.8	40	7	459	12.8
Intensive care units	3	0.4	2	0	3	0.4	10	1.1	7	1	25	0.7
EOL beds	35	4.7	19	3	17	2.2	9	1.0	15	3	95	2.6
Outpatients	54	7.3	38	6	59	7.6	59	6.3	25	5	235	6.6
Community referral	56	7.6	45	8	40	5.2	146	15.7	42	8	329	9.2
No data*	11	1.5	10	2	5	0.6	34	3.7	58	11	118	3.3
Diseases referred												
AIDS	14	1.9	2	0.3	10	1.3	8	0.9	3	0.5	37	1.0
COVID-19	-	-	-	-	-	-	135	14.5	93	16.9	228	6.4
End-stage cardiac failure	78	10.6	43	7.3	64	8.3	21	2.3	14	2.5	220	6.1
End-stage COPD	20	2.7	58	9.8	32	4.1	25	2.7	19	3.4	154	4.3
End-stage dementia	24	3.3	42	7.1	33	4.3	20	2.1	16	2.9	135	3.8
End-stage liver failure	11	1.5	10	1.7	12	1.6	7	0.8	1	0.2	41	1.1
End-stage renal failure	125	17.0	101	17.0	109	14.1	143	15.4	58	10.5	536	15.0
Major CVA	26	3.5	20	3.4	8	1.0	18	1.9	11	2.0	83	2.3
Metastatic cancer	320	43.4	234	39.5	374	48.4	447	48.0	268	48.6	1643	45.8
Progressive neurological	72	9.8	25	4.2	56	7.2	27	2.9	19	3.4	199	5.6
Tuberculosis	3	0.4	3	0.5	9	1.2	11	1.2	3	0.5	29	0.8
Other	34	4.6	55	9.3	52	6.7	54	5.8	41	7.4	236	6.6
No data*	10	1.4	-	-	14	1.8	15	1.6	5	0.9	44	1.2
Average level of functionality												
Bedbound	348	47.2	243	41.0	292	37.8	411	44.1	228	41.4	1522	42.5
Fully mobile	97	13.2	93	15.7	125	16.2	130	14.0	81	14.7	526	14.7
Requires assistance	281	38.1	248	41.8	346	44.8	366	39.3	224	40.7	1465	40.9
No data*	11	1.5	9	1.5	10	1.3	24	2.6	18	3.3	72	2.0
Referred for end-of-life care												
Yes	644	91.3	272	46.9	578	75.6	344	37.3	197	36.1	2035	57.9
No data*	32	4.3	13	2.2	10	1.3	9	1.0	5	0.9	69	1.9

PC, palliative care; EOL, end of life; COPD, chronic obstructive pulmonary disease; CVA, cerebral vascular accident.

Time PC Referral to Death, n = 1894

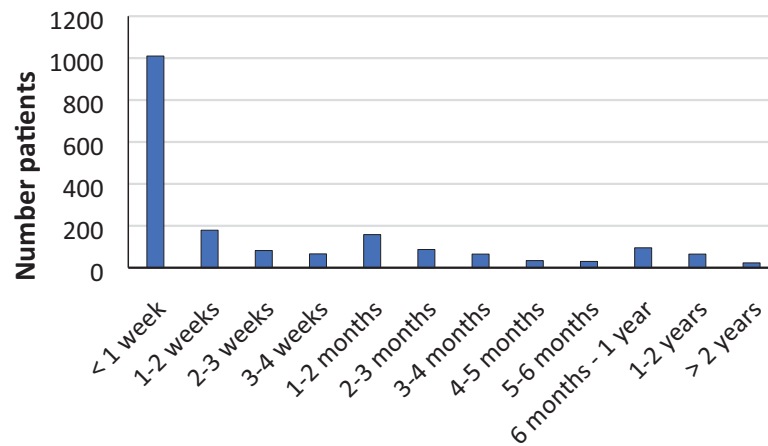


Figure 2. Time of PC referral to death. PC, palliative care.

Table 3. Place of death.

Place of death	2017		2018		2019		2020		2021		Overall	
	n	%	n	%	n	%	n	%	n	%	n	%
Place of death n = 1188												
Home	45	6.1	48	8.1	54	7.0	29	3.1	16	2.9	192	5.4
Hospice	3	0.4	5	0.8	4	0.5	1	0.1	5	0.9	18	0.5
Hospital	125	17.0	164	27.7	145	18.8	334	35.9	202	36.7	970	27.1
Intermediate care	1	0.1	1	0.2	1	0.1	1	0.1	0	0.0	4	0.1
Other	2	0.3	1	0.2	0	0.0	0	0.0	1	0.2	4	0.1
No data*	561	76.1	374	63.1	569	73.6	566	60.8	327	59.3	2397	66.9

pain and symptoms are important markers by which other staff evaluate the impact of a VNLDS:

For me, it is when they come and initiate the pain control; it helps the patient a lot. The patient is then very comfortable and so. The palliative care is good, they tick all the boxes. (Wardstaff2)

Psycho-social and spiritual referrals

The database and documentation indicate that 100% of the patients received psycho-social support. The majority (89,6%) of the patients are classified by their social circumstances by the hospital as ‘poor’ (family unit earns less than

R100,000 per year); (51,4%) or ‘very poor’, which is classified as formally unemployed, no formal income (38.2%), emphasizing the need for social support:

Is the patient working? If the patient is still working, I do it. Referral to the social worker so that I, the social worker can help the patient with the work papers. (Pallsocial1)

Interviews with the VNLDS show that the team also links with a multifaith spiritual team who liaises with the team daily. There is evidence in the documentation of routine spiritual assessment and referral to a spiritual team.

Informed and participatory decision-making

The interviews with the VNLDS indicated that the treating teams must break bad news and share prognoses. However, the VNLDS service assesses patients' understanding of the disease and prognoses and assists in deepening this understanding and exploring care options with both the patient and family. Routine data collected by the service indicate an average of 50 family meetings a month, and there is a specific family meeting stationery in the documentation analysed, including educational material provided to patients and family education of the illness, the care and medication that is and will be required.

Bereavement care

There is evidence of bereavement follow-up (28.9%), and the stationery includes a section to record a bereavement call. However, most patients are referred to community resources for PC and bereavement care after discharge.

Patient and family education. This domain is both clinically and organizationally important. Patient and family educational material in the form of pamphlets is available. Staff outside the VNLDS service identify the role of the VNLDS service inpatient and family education as a positive contribution to care and empowers the family to continue on their own:

There are patients, the family members, actually, I've seen the family members before palliative team is involved and after you the PC, are involved. And there's a huge difference. There's, there's the unanswered questions, you know, the PC answer those questions. The family members feel the sense of, not so much control, but understanding, so they they've come to terms with what is to be expected, and what they can do. So, that they actually have this, this empowerment. (Wardstaff3)

Dimensions associated with professional integration

The provision of collaborative care

The provision of collaborative care is conceptualized as the appliance of automatic triggers, multidisciplinary care provision, ensuring continuity of care and the provision of end-of-life care across the hospital.^{10,23}

The use of automatic triggers to initiate PC

There is divergent evidence on applying automatic triggers on when to refer to PC. There is documentation (a referral sheet and a PC indicator tool). Still, the referral patterns demonstrate that mainly cancer patients (45%) (Table 1) are referred with few cardiac patients (6%) and HIV and TB patients (1.5%) referred, suggesting that the indicator tool is not used regularly. There is further evidence that referrals are late in the disease trajectory:

I do not know if all the patients (needing palliative care) are referred to palliative care. (Wardstaff3)

Multidisciplinary care implementation. There is very little evidence of multidisciplinary care during the evaluation period at GSH. According to the VNLDS staff interviews, the PC team works and provides care as an interdisciplinary team. However, the PC is linked but not integrated into the ward teams. The VNLDS refers to rehabilitative services. This lack of multidisciplinary has not been impacted by the VNLDS:

It's more the doctors that are giving the orders. There's no multidisciplinary approach. There's no, like a combined view on the patient. So, if there's a doctor's rounds, the nurse will accompany the doctor and take the orders. (Pallnurse2)

Yes, so I don't; I don't think the nursing staff feel empowered enough to actually make suggestions, not only with regards to the palliative team, but I mean with any other, whether it's dietitian or, you know, if there's any social services. (Wardstaff1)

Ensuring continuity of care. According to the literature, PC systems integration occurs when there are clinical care pathways for patients to ensure continuity of care. The VNLDS refers patients to Community Health Care and Hospices. The service also follows the patients up 1 week after discharge to ensure community care is in place:

Then I do a follow up with the patient to see if they got the community key services; then if not, I will follow up with the coordinator working in that specific area where the patient stays to find out the delay. (AdminPC)

The provision of end-of-life care. Documents provide evidence that comprehensive end-of-life care

is provided for patients referred to PC but not to all dying patients in the hospital:

And it's almost like they want to push the patient to a side cubical, fine when they are dying. (Wardstaff2)

Dimensions associated with organizational integration

The availability of information systems

Drawing from the literature, one of the aspects of organizational integration is that there are monitoring and evaluation tools available to evaluate the PC in the hospital.¹⁶ Currently, there are monitoring and evaluation services available in the VNLDS but no other PC monitoring and evaluation in the hospital.

There is evidence of monitoring within the service:

And yes, then also daily daily, weekly, monthly. I will do the stats. (PCAdmin)

However, outside the service, the outcomes of patients who need PC are not always known:

No, I may not always know the outcomes of those patients. (Wardstaff2)

Education in PC at various levels. Conceptually, PC education should be provided at various levels.¹ Furthermore, continuous medical education and patient and family education should be available.²⁵

Basic education

There is evidence that 100 of the 3400 healthcare professionals employed by GSH³² from various disciplines have been trained in basic PC. From the interviews with the VNLDS staff, 100 HCPs in the hospital have received basic PC training. The VNLDS service is involved in final year medical students' training once a week and in the training of Gynaecology Oncological Fellows.

Intermediate education

From the interviews, family physician registrars rotate for 6 weeks through the service. There is also intermediate training for oncology registrars in the hospital linked to the university. However, neither family physicians nor oncologists refer to

the VNLDS. There is no further intermediate-level training in the hospital.

Advanced training

From the interviews, there is no advanced PC training in the hospital. Both the doctors volunteering in the VNLDS service have specialized PC training.

Continuous medical education

The documentation indicated that the VNLDS provided a quarterly lecture as continuing education on PC open to the hospital but this stopped during COVID-19. There is an acknowledgment that there is a need to provide further continued education in PC across the hospital:

There needs to be more empowerment of the current team in the ward and further continuous education. (Pallnurse2)

Leadership and governance

Data analysis included a review to assess whether there is a strategic plan for PC in the hospital, managerial oversight and accountability, financial and resources support and clinical leadership.

No strategic PC plan was found. There is documentation evidence of clinical, administrative managerial oversight through minutes of meetings. Quarterly meetings are held with management as a whole team, and staff report to their clinical managers weekly. Medical clinical leadership is provided by university staff.

Guidelines and policies

Hospital documentation was reviewed for integrated guidelines and standard operating procedures to provide evidence of organizational integration. Stand-alone guidelines and policies do exist in the VNLDS but not in other areas of the hospital:

No, I don't, I don't have any policies. I was actually going to speak to sister at palliative care because we need, not only an SOP for nursing, but also if we can actually incorporate it from doctors as well. (Wardstaff1)

Five documents were found as stand-alone policies or guidelines supporting the VNLDS PC

service. PC was integrated into one stand-alone PC chapter in the surgical guidelines and one question in the home oxygen referral system.

PC workforce and resource support

Two professional nurses, two auxiliary social workers and a clerk are employed in PC by the hospital. The university employs medical doctors volunteering in the hospital. The professional nurses are not in dedicated PC posts. The VNLDS have a dedicated office, family meeting and teaching space. The university contributes to the resources of the service. There is a debriefing service for the PC staff. There are two further nurses in the hospital with intermediate PC training in other departments who work in oncology and surgery.

The availability of essential PC medication. Essential medications, as specified by the WHO Essential PC Medicine list, are all available in the hospital.

Researching PC. There is evidence of PC research in the VNLDS but no evidence of dedicated PC research outside the service.

Normative integration (norms, values, behaviour)

There is the assumption that PC services are only for end-of-life care. This assumption has not been changed by the VNLDS:

I think that most are walking around with the assumption or going around with the assumption that palliative care is just for patients who are going to die or are now diagnosed with cancer and they gonna die at the end of the day. (Pallnurse2)

The behaviour of avoidance of end-of-life care and referring when no further curative management can be done has been shifted by the VNLDS service as evidenced by more patients being referred for reasons other than end-of-life care.

The outside wards value the VNLDS service for both clinical and staff care. The PC staff has assisted the ward staff in managing their distress and has assisted in creating spaces, like a butterfly, room for reflection:

The palliative care sister assisted us in addressing the moral distress and how to manage death and dying. (Wardstaff3)

Normalizing

The VNLDS service has become part of routine care, contributing to the service's acceptability and value:

Um, you know, I think, I think what makes a big impact is to see people who do it regularly. So, I think, I think people talk about palliative care and refer to palliative care more because they see it happen, uh, and they see the clinical benefit of it. So, I think it's a bit of a chicken and egg situation, but I think the, the more active a palliative care team is in a ward with clinical decision making, uh, the more it's used and the more valuable it becomes and the more engaged with it other doctors are. (Wardstaff4)

Discussion

The extent of integration achieved

The VNLDS service has successfully implemented the integration of PC at a clinical level, in accordance with the recommendations outlined in the conceptual framework, across the majority of hospital wards.¹¹ There is both quantitative and qualitative evidence of pain and symptom control, family involvement, and patient and family education.^{18,25} The VNLDS has demonstrated the importance of family meetings, which empower patients and families in decision-making. Carolan *et al.*³³ highlighted that family distress may have a significant ripple effect, impacting the entire family system. Family meetings are thus core to assessing family structure, support and educating patients and families on the required care, as essential components of a PC service.^{18,25,27} The impact of family support by the VNLDS has allowed most patients to be discharged home with referrals to support from home-based care organizations rather than dying in the hospital. Continuity of care is further strengthened by linking them with community services.²⁵ Linking hospital PC and networking beyond the hospital is essential to both clinical hospital integration and strengthened PC care in the community system.²⁸

How the service improved the valuing of PC and PC integration

The clinical service expansion is attributed to observing the positive outcomes of working with the PC team. As stated by one of the participants, '*the more you see it, the more valuable it becomes*'. Observing the positive engagement and improved

outcomes of referred patients and their families ensures value is assigned to PC, which assists in integration. Patients' continuity of care is ensured; most patients referred to the GSH PC service are discharged and receive PC in the community and die at home. These observed perceived benefits and compatibility with current service needs affected the adaptability of the PC approach.¹⁶ Users are more receptive to the PC approach, which, in turn, provides legitimacy to the PC service.¹⁶ For example, a senior staff member states that the VNLDS makes a 'huge difference', and subsequently, this unit refers to PC regularly.

The acknowledgement of the impact of the end-of-life is as important for staff as it is for their patients. The open engagement with the suffering and actual dying process has assisted in addressing the staff's personal moral distress, which has been an important finding of this research study. PC has provided staff outside the VNLDS with the tools to care and also to engage with their own home and work experiences openly. For example, a butterfly room was opened in a ward as a place for contemplation for families and staff. Subsequently, vulnerability around death and dying is respectfully acknowledged and managed in this ward. There is thus a realization of the benefit of PC service through attending to the staff's needs, which enhances the receptiveness towards PC.¹⁶

Limitations in the extent of clinical integration

Unfortunately, most patients are referred for end-of-life care, an average of 7 days after hospital admission. In addition, most of these patients already require assistance with activities of daily living or are fully bedbound. Therefore, the fully recognized impact of early specialized PC services has yet to be reached as demonstrated in global research.²⁸ For example, Temel *et al.*³⁴ demonstrated that specialized PC services early in the disease trajectory of patients with metastatic lung cancer improve quality of life, reduce anxiety and depression in patients and marginally prolong life. However, as indicated by this research and other studies, late referrals to PC may result from an assumption that PC is only for actively dying patients.^{3,35} This, together with the observed behaviour of avoidance of patients at the end of their lives, may result from limited, late referrals.³⁶ The medical world has assisted in what Sallnow *et al.*³⁵ describe as an 'unbalanced' societal approach to death, dying and grieving focuses

on unnecessary clinical interventions and may exclude the psycho-social and spiritual dimensions of dying. Therefore, the referral to PC services may be convenient at this stage of care to avoid the dying process and accompanying complex care and emotions. Subsequently, this behaviour of disengagement with patients at the end of their lives may also cause disengagement with the whole PC process, and not recognizing the benefit of PC at an early stage of the disease trajectory. However, this behaviour is challenged by the VNLDS service by persistently stating that PC starts long before the end-of-life. Subsequently, one of the normative aspects of integration accomplished by the VNLDS service is the normalization of death in accordance with the WHO definition of PC and a global movement to value death and dying as an important and integral part of life.^{35,37,38}

A further limitation in the extent of integration is that VNLDS is not reaching all disease-specific populations that require PC. The incidence of metastatic cancer patients referred to the VNLDS compared to other life-threatening illnesses and the causes of mortality in South Africa are disproportionate.⁶ In South Africa, TB, diabetes, cerebrovascular disease, heart disease and HIV were the leading causes of death in 2018.³⁹ Despite this, very few TB and HIV patients (1.5%) were referred to the VNLDS, and of note, the cardiology outpatients were the lowest source of outpatients referrals. This disproportionate referral pattern leaves many patients with cardiac and infectious diseases without access to PC. Automatic triggers and awareness on when to initiate PC are well established within oncology, but in organ failure and infectious diseases, PC needs are not met.⁴⁰ The VNLDS service has initiated automatic triggers in patients with pancreatic adenocarcinoma and end-stage renal patients, which are reflected in the referral patterns. For example, all patients in GSH who are declined for dialyses are automatically referred to PC services.⁴¹ This is evident in the number of patients with renal failure referred to PC. However, the PC service currently works mainly on voluntary referral and linkage has not been uniformly successful. Automatic triggers specific to the context are thus core to further integration and universal PC access.⁴² The SPICT-SA indicator, specifically designed for South Africa, considers the unique patient burden and wide range of patients who require PC.⁴² The assumption that PC is only for metastatic cancer or EOL

care is a significant assumption that requires further professional interaction to address this gap in access to PC.

Enabler

This commitment and the drive to integrate PC on a professional level comes from inside the VNLDS service and the university's Faculty of Health Sciences. The VNLDS staff are passionate and committed to integrating PC. Rhee *et al.*⁴³ identified factors affecting PC integration in Africa and named advocates and pioneers as key factors driving integration. However, they warn that integration fuelled only by advocates is high risk as sustainability further requires other strategies and infrastructure support.⁴³ PC being driven by only a small group of passionate PC advocates, lack of commitment from organizational leadership, limited trained PC staff and lack of PC education are all factors in GSH echoing barriers experienced across the African continent.⁴³ Sustainable PC leadership in the hospital and across Africa will be important to ensure PC integration. Admittedly, moving this paradigm is beyond a clinical service and was thus not achieved by the VNLDS service.

Linking PC to the prevailing culture

The organizational culture of siloed service delivery results in a need for more professional integration across all disciplines, including PC. Disciplines stay in their 'own lane' and that is the 'way things are done'. Most services in the ATH are only at a level of integration where services are linked with doctors working in parallel and disciplines functioning in their siloes.¹⁵ It may be ambitious to imagine a horizontal PC service in a hospital with limited PC-trained staff, where disciplinary excellence is core to organizational culture.⁷ Consequently, a PC service that is only linked may be appropriate, at first, within the ATH context to align with the prevailing culture of vertical excellence. However, currently, innovation and technical excellence are celebrated, and an intervention that deals with death and dying may not be perceived as key. Although the VNLDS service is valued, it does not yet form part of 'excellence'. Labelling PC as excellent care is one of the most significant paradigm shifts to normalize PC and align it with the prevailing culture of excellence. The prevailing structure of 'how things are done' will be important as the initial pathway in integration.^{12,16} To ensure this,

linkage across all the appropriate disciplines will not be successful if further aspects of functional integration do not anchor it at all levels of care.²⁸

Limitations in functional integration

This lack of functional integration is evident when we observe that nurses are not in dedicated PC posts, there is no PC strategic plan, and the accountability structures are not integrated. Atun *et al.*¹⁶ advise that integrating an intervention into the broader health system governance structure will require alignment with existing regulatory mechanisms, creating unified accountability frameworks, integrating reporting and establishing a joint performance management system.¹⁶ All of the above integration structures mentioned by Atun require action on an organizational level. This action can be unpacked as decision-making, commitment, support and willingness of key leaders to achieve PC integration.¹⁹ Furthermore, the current GSH team needs to conform to the recommended staffing, especially the requirement for PC-trained nurses and medical doctors.⁶ Kaasa *et al.*¹⁸ confirm the lack of trained PC specialists is a substantial barrier to the integration of PC and hampers the confidence by which other specialists refer to PC services. Furthermore, as stated above, this impact of limited-service delivery and specialist PC training in an ATH may impact beyond the ATH. This is evident when we review the limited research and education in the PC discipline, which impacts nationally and in the rest of Africa.⁴⁴ This need for whole system integration is especially evident when we evaluate the lack of PC education in South African ATHs. Physicians and surgeon trainees receive no PC training, and there are no PC mentors in these departments due to the absence of PC-trained consultants in most ATH. Overloaded curricula and services may underpin this lack of training, resulting in ATHs' workforce having very limited PC knowledge and skills. However, the Departments of Radiation Oncology across South Africa have successfully integrated a PC course into registrars' training without overburdening registrars or consultants.⁴⁵ This leaves the VNLDS as a small group of healthcare workers within the hospitals with PC skills.

This lack of investment in PC may be an overburdened and under-resourced healthcare system, and another new intervention may be deemed an extra burden on the healthcare system.⁴⁶ GSH is a well-functioning hospital in South Africa but

is also overburdened by limited resources. Waddington and Egger⁴⁷ highlight that integration of new interventions is not always welcomed because, in a system where the wider health system is not functioning well (South African health-care sector), it is questionable to change aspects of the system that are working. Furthermore, a new intervention has to demonstrate a significant impact on cost containment.⁴⁷ Unfortunately, the VNLDS service has no economic evidence that it is cost-effective apart from discharging 72% of patients home for EOL care. The need for contextually specific economic evidence is paramount to enable further integration. This is further complicated by the limited research and costing models for PC in low-resource settings.^{48,49} Shifting the functional aspects of integration will require economic commitment from leaders and willingness and commitment to integrate PC.

Limitations

This is embedded research and the researcher is explicit about her support of PC, which may introduce bias with stakeholders and their responses to her. Most of the data were obtained through interviews and participants may also have recall bias. Participants not in favour of PC integration may also not want to be interviewed, which may limit counterfactual information.

Data in the databases also depend on the actual input of the records. However, as part of the database management process, data are validated regularly following set data management operating procedures. The limitation of the database was that it contained limited data on the patients' deaths.

Conclusion

The VNDL service has been able to harmoniously integrate clinical PC services in specific units and disease profiles and has brought about an organizational culture of normalizing a PC approach. Observation of the service by hospital staff outside of the specific units and realizing the benefits have further contributed to the adoption of PC integration. However, PC has yet to be adopted across all units or disciplines. The context of vertical service delivery among all disciplines and the lack of organizational integration may underpin the reasons for this. In conclusion, PC integration will require organizational commitment and economic evidence to ensure

PC integration in an ATH to have an overall impact on national PC integration.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the University of Cape Town Human Ethics Committee (HREC 071/2020) and site permission was obtained from GSH. The REDCap database creation and data analyses received ethics approval from the UCT Human Ethics Committee (HREC R012/2016).

Consent for publication

Consent to publication was obtained from participants.

Author contributions

Rene Krause: Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Methodology; Project administration; Writing – original draft.

Liz Gwyther: Supervision.

Jill Olivier: Supervision.

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Competing interests

The authors declare that there is no conflict of interest. This article will contribute to the main authors PhD study.

Availability of data and materials

Anonymized data are available from the corresponding author upon reasonable request. All data are stored on a REDCap database and protected storage devices and can be accessed with permission.

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Appendix A

Corroboration of findings

Clinical integration.

Sub-themes	Database	Documents	Thematic analysis	Inference
Pain and symptom control	97% of patients received symptom control 83% of patients referred are bedbound or require assistance	Evidence of routine pain and symptom control in PC stationery (assessment form)	Nurses in the VNLDS and the wards indicated that the VNLDS service plays a valuable role in managing pain and symptoms.	There is strong converging evidence that patients who are referred to PC receive pain and symptom control.
Psycho-social and spiritual care	100% of patients or families received psycho-social support 89.6% of patients referred to PC are from poor to very poor backgrounds	Evidence of routine assessment of psycho-social and spiritual needs in stationery Evidence routine spiritual care assessment	Social auxiliary workers do an assessment and if need be refer to social workers.	Psycho-social support forms a large part of the PC services because patients are from poor backgrounds. The PC team also sees the patient at the point of diagnosis where patients have to adapt to the new reality of living with a life-threatening illness and families need to be informed.
Informed participatory decision-making	An average of 50 family meetings per month	Family meeting stationery used in service	This is a core role of the VNLDS.	Resources demonstrate convergent results of patients and families being part of the decision-making process.
Bereavement call	Evidence of only 5% of patients receiving bereavement care	Evidence of stationery including bereavement calls	No reference to bereavement care	Divergent evidence. This may be because there is no permanent social worker attached to the service and most patients are referred to community care after discharge. This is thus an identified need but not delivered in the hospital.
Patient and family education		Patient and family education material available	Staff in and outside the VNLDS identify the role of the VNLDS in patient and family education, and places value on this service.	There is convergent data that patients and families who are referred to PC receive education.

PC, palliative care; VNLDS, vertical nurse-led doctor-supported.

Professional integration.

Sub-themes	Data	Documentation	Interviews	Inferences
Automatic triggers	Referral patterns: Metastatic cancer 45%, end-stage renal failure 15%, end-stage cardiac failure 6%, HIV and TB 1.5%	Referral sheet to PC has indicators and a local PC indicator tool available but not applied	VNLDS have automatic triggers but staff outside the service are not aware.	Divergent evidence that HCPs do not know when to refer to PC services across all diseases. Triggers across all illnesses are not used.
Multidisciplinary care provided		Evidence of routine assessment for rehabilitative care and if needed referral rehab services Attendance register of daily ward rounds	The VNLDS functions as an IDT but has minimal MDT involvement In the wards, the decisions are made by the doctors	Divergent results. The PC team works as an interdisciplinary team and provides care in an interdisciplinary fashion. However, the PC is linked but not integrated into the ward teams. The VNLDS will refer to rehabilitative services.
Clinical care pathways to ensure continuity of care	An average of 61% of patients are referred to home base care organizations An average of 28% of patients are referred for hospice care	Hospice referrals and home base care referrals form part of the routine assessment Follow-up calls form part of the routine care	Follow-up care is supported by multiple PC staff and ward staff	This is a fundamental aspect of the services provided by the ATH to link care across the clinical platform.
Integrated EOL care	56.6% of patients received EOL care delivered by the PC team	There is a SOP for end- of-life in the hospital	Ward staff identify that not all dying patients are referred to the VNLDS and that there is no application of the end-of-life SOP	The PC does deliver EOL care but not all the dying patients are referred to the PC team. The integrated approach to all deaths is missing

ATH, Academic Teaching Hospital; PC, palliative care; VNLDS, vertical nurse-led doctor-supported; MDT, multidisciplinary team; IDT, interdisciplinary team; SOP, standard operating procedure; HCP, health care professional; CEU, state continues education.

Organizational integration.

Themes	Database	Documents	Interviews	Explain
Information systems		PC report includes: <ul style="list-style-type: none"> • Number of new patients • Number of PC visits • Home base care referrals • Hospice referrals • Number of deaths • Number of re-admissions • Number of follow-up phone calls • Number of bereavement calls 	Inside the service <i>'And yes, then also daily on a daily basis, weekly, monthly. I will do the stats.'</i> [APC] Outside the service <i>No, I may not also know the outcomes of those patients.</i> [OPN2]	The results demonstrate the service is linked and not integrated.
Basic education		100 HCPs received basic PC education 1 Gynaecologist trained per year All final year medical students spend one morning with the PC service in GSH (48 h in total across the whole 6 years)	The VNLDS identify that people are poorly informed about PC.	Limited amount of permanent staff trained in basic PC

(Continued)

Appendix (Continued)

Themes	Database	Documents	Interviews	Explain
Continuous education		There were 105 staff members trained to use syringe drivers in 2021 Attendance registers of journal club meetings before COVID	A need is identified for CEU in the wards.	Divergent evidence The need for CEU
Intermediate education		Learning plan and online material for the registrars	3 Family physicians trained per year Weekly teaching ward rounds with the oncology team. (Combined Care Ward Round)	The family physicians and the oncologist do not refer to the PC team and are expected to deliver most of their PC. There is evidence of inadequate multidisciplinary education.
Leadership and governance		Meeting minutes Quarterly meetings with hospital managers Staff report to own managers (nursing reports to nursing) No strategic plan	No mention	The lack of a strategic plan agreed upon across the hospital
Financial and resource support			2 Professional nurses, 2 auxiliary social workers and a clerk staff are employed in PC by the hospital. The university employs the medical doctors. The professional nurses are not in dedicated PC posts. The university contributes to the resources and support of the service.	
Integrated guidelines		One stand-alone PC chapter in the surgical guidelines and one integrated question in the home oxygen referral system	No PC policies or SOP identified	Limited integrated guidelines
Stand-alone PC guidelines and policies	5 stand-alone standard operating procedures are available	<ul style="list-style-type: none"> • End-of-life SOP • Syringe driver SOP • Standard assessment guideline • Standard family meeting documentation Referral processes to outside organizations.	Multiple forms and SOP identified	There is convergent evidence of guidelines and policies supporting PC service delivery.
Essential PC drugs available		Treatment guidelines and essential medicine list Hospital adults	All the drugs are available	There are no limitations on drugs
Support for staff			Debriefing For PC staff sessions with an outside organization PC staff involved in debriefing staff	There are debriefing services available for PC staff, and the PC staff are involved in debriefing staff.
GSH, Groote Schuur Hospital; PC, palliative care; VNLDS, vertical nurse-led doctor-supported.				